Quality Standards

Palliative Care

Care for Adults With a Progressive, Life-Limiting Illness

Health Quality Ontario

Let's make our health system healthier

Ontario Palliative Care Network

Summary

This quality standard addresses palliative care for people who are living with a serious, life-limiting illness, and for their family and caregivers. The goal of palliative care is to relieve pain and suffering, and to improve a person's quality of life. This quality standard focuses on care for people in all settings, including home and community, hospice, hospital, and long-term care.

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About Quality Standards

Health Quality Ontario, in collaboration with clinical experts, patients, residents, and caregivers across the province, is developing quality standards for Ontario. Health Quality Ontario has worked in partnership with the Ontario Palliative Care Network to develop this quality standard.

Quality standards are concise sets of statements that will:

- Help patients, residents, families, and caregivers know what to ask for in their care
- Help health care professionals know what care they should be offering, based on evidence and expert consensus
- Help health care organizations measure, assess, and improve their performance in caring for patients

The statements in this quality standard do not override the responsibility of health care professionals to make decisions with patients, after considering each patient's unique circumstances.

How to Use Quality Standards

Quality standards inform clinicians and organizations about what high-quality health care looks like for aspects of care that have been deemed a priority for quality improvement in the province. They are based on the best available evidence.

They also include indicators to help clinicians and organizations assess the quality of care they are delivering, and to identify gaps and areas for improvement. These indicators measure processes, structures, and outcomes.

In addition, tools and resources to support clinicians and organizations in their quality improvement efforts accompany each quality standard.

For more information on how to use quality standards, contact **qualitystandards@hqontario.ca**.

About This Quality Standard

Scope of This Quality Standard

This quality standard addresses care for adults with a progressive, life-limiting illness, and for their family and caregivers. It focuses on palliative care in all health settings, for all health disciplines, and in all health sectors. It includes information about general palliative care that applies to all health conditions. Palliative care can benefit individuals and their caregivers as early as at the time of diagnosis of a progressive, life-limiting illness through the end of life and bereavement.

Condition-specific palliative care may be addressed in other quality standards. Although this quality standard includes information that could apply to infants, children, and youth, a separate palliative care quality standard is being considered for these populations.

This document does not address medical assistance in dying. People who choose medical assistance in dying should receive high-quality palliative care. Health care professionals are expected to manage all requests for medical assistance in dying in accordance with the expectations set out by their regulatory colleges. Health care professionals should refer to their regulatory colleges for more information and guidance on medical assistance in dying.

Terminology Used in This Quality Standard

In this quality standard, “health care professionals” refers to regulated professionals, such as registered nurses, nurse practitioners, pharmacists, physicians, physiotherapists, psychologists, occupational therapists, social workers, and speech-language pathologists.

We use the term “health care providers” when we are also including people in unregulated professions, such as personal support workers, behavioural support workers, and administrative staff. We use the term “interdisciplinary health care team” when we refer to all individuals who are involved in providing care (including health care professionals and health care providers).

Why This Quality Standard Is Needed

Palliative care (also known as hospice palliative care) refers to the relief of suffering and improvement of the quality of living and dying, using a holistic approach.[1] Palliative care addresses people's physical, psychological, social, spiritual, and practical needs, as well as their associated expectations, hopes, and fears. It helps people with a progressive, life-limiting illness and their family prepare for and manage end-of-life choices, the process of dying, and coping with loss and grief.[1,2] Palliative care does not focus just on end-of-life care; a palliative approach to care can begin upon the diagnosis of a life-limiting illness. People can receive palliative care while actively receiving treatment for their disease.

Despite the clear benefits of palliative care, there are many gaps in its delivery in Ontario, including access to palliative care services. Of the about 94,500 people who died in Ontario between April 2015 and March 2016, about 56,000 (59%) received palliative care services on at least one occasion in their last 12 months of life.[3]

Among people who died in Ontario in 2015/2016, about a quarter (24.1%) received physician home visits, and about one-third (27.5%) received palliative-specific home care in their last month of life.[3] Receiving palliative home care has been associated with a 50% reduction in the likelihood of dying in hospital.[2,4,5] Furthermore, more than half (54.8%) of people who died in Ontario had unplanned visits to the emergency department in their last month of life.[3]

Whether or not people are able to die in the place they choose also reveals gaps in the provision of palliative care across the province. In surveys of patients and caregivers, most say they would prefer to die at home.[2,6] And yet, of the about 94,500 people who died in 2015/2016, 53.6% died in hospital.[3] Increased access to palliative-specific home care and home visits from physicians could reduce the number of people who die in hospital.[2]

Equity is also an issue in the delivery of palliative care. In 2015/2016, patients living in poorer neighbourhoods were less likely to receive palliative home care services in their last month of life (22.7%) than patients in the richest neighbourhoods (32.2%).[2]

Income is one equity issue, but there is also a need for culturally sensitive services to meet the diverse needs of all Ontarians. This includes access to culturally appropriate and safe palliative care across urban, rural, and remote communities, and includes various cultural, faith, and linguistic groups, and vulnerable populations.[7]

The 13 quality statements that make up this quality standard are based on the best available evidence and guided by expert consensus from health care providers and people with lived experience. The statements provide guidance for areas identified by the Ontario Palliative Care Network and Health Quality Ontario's Palliative Care Quality Standard Working Group as having high potential for improvement in the way palliative care is currently provided. Each statement has accompanying indicators to help health care providers and organizations measure the quality of the care they provide, and includes details on how successful delivery can improve palliative care and quality of life for people living with a progressive, life-limiting illness, their family, their caregivers, health care providers, and health services at large.

Principles Underpinning This Quality Standard

This quality standard is underpinned by the principles of respect, beneficence, autonomy, justice, and equity.

People should receive palliative care services that are respectful of their rights and dignity. Person-centred care—compassionate care that respects people's wishes, beliefs, and values by promoting autonomy, dignity, and inclusion in shared decision-making as appropriate—is fundamental to an ethics-based palliative approach to care.[8]

A high-quality health system is one that provides good access, experience, and outcomes for everyone in Ontario, no matter where they live, what they have, or who they are.

People who have a progressive, life-limiting illness should be offered services that are respectful of their gender, sexual orientation, socioeconomic status, housing, age, background (including self-identified cultural, linguistic, ethnic, and religious backgrounds), and disability.

Equitable access in the health system also includes access to culturally safe care. Language, a basic tool for communication, is an essential part of safety of care and needs to be considered throughout a person's health care journey. For example, in predominantly Anglophone settings, services should be actively offered in French and other languages.

Care providers should be aware of the historical context of the lives of Canada's Indigenous peoples and be sensitive to the impacts of intergenerational trauma and the physical, mental, emotional, and social harms experienced by Indigenous people, families, and communities. This quality standard uses existing clinical practice guideline sources developed by non-Indigenous groups, which may not include culturally relevant care or acknowledge traditional Indigenous beliefs and practices.[9,10] Therefore, it is important for care to be adapted to ensure that it is culturally appropriate and safe for First Nations, Inuit, and Métis peoples in Ontario.

How Success Can Be Measured

Health Quality Ontario has worked with the Ontario Palliative Care Network to ensure that selected measures for this quality standard are aligned with provincial measurement initiatives.

The Palliative Care Quality Standard Working Group identified a small number of overarching goals for this quality standard. These have been mapped to indicators that may be used to assess quality of care provincially and locally.

How Success Can Be Measured Provincially

- Percentage of people who receive care in their last 12 months, 3 months, and 1 month of life:
  - Home care services (any home care and palliative-specific home care)
  - Health care provider home visits (currently only physician home visits are measurable)
  - Hospice care (currently not measurable)

- Percentage of people who had 1 or more unplanned emergency department visits in their last 12 months, 3 months, and 1 month of life
- Percentage of deaths that occurred in:
  - Hospitals
    - In-patient care
    - Emergency department
    - Complex continuing care
    - Palliative care beds (currently not measurable)
  - Long-term care homes
  - The community (may include home, hospice residence, retirement home, or assisted-living home)
- Percentage of people who receive palliative care (or their caregivers) who rated overall care received in their last 12 months, 3 months, and 1 month of life as excellent
  - Example of a question from the CaregiverVoice Survey: "Overall, and taking all services in all settings into account, how would you rate his/her care in the last 3 months of life?" (Response options: "Excellent, Very good, Fair, Good, Don't know")[11,12]
  - Note: as of 2017, 25 hospice residences in Ontario had adopted the CaregiverVoice Survey, and about 11 of 14 local health integration networks had adopted this survey for patients as end-of-life home care clients.

How Success Can Be Measured Locally

You may want to assess the quality of palliative care you provide to people. You may also want to monitor your own quality improvement efforts. It may be possible to do this using your own clinical records to measure the indicators above, or you might need to collect additional data.

In addition, each quality statement within this standard is accompanied by one or more indicators. These indicators are intended to guide the measurement of quality improvement efforts related to the implementation of the quality statement.

Quality Statements in Brief

QUALITY STATEMENT 1:
Identification and Assessment of Needs

People with a progressive, life-limiting illness have their palliative care needs identified early through a comprehensive and holistic assessment.

QUALITY STATEMENT 2:
Timely Access to Palliative Care Support

People with identified palliative care needs have access to palliative care support 24 hours a day, 7 days a week.

QUALITY STATEMENT 3:
Advance Care Planning—Substitute Decision-Maker

People with a progressive, life-limiting illness know who their future substitute decision-maker is. They engage in ongoing communication with their substitute decision-maker about their wishes, values, and beliefs, so that the substitute decision-maker is empowered to participate in the health care consent process if required.

QUALITY STATEMENT 4:
Goals of Care Discussions and Consent

People with identified palliative care needs or their substitute decision-makers have discussions with their interdisciplinary health care team about their goals of care to help inform their health care decisions. These values-based discussions focus on ensuring an accurate understanding of both the illness and treatment options so the person or their substitute decision-maker has the information they need to give or refuse consent to treatment.

QUALITY STATEMENT 5:
Individualized, Person-Centred Care Plan

People with identified palliative care needs collaborate with their primary care provider and other health care professionals to develop an individualized, person-centred care plan that is reviewed and updated regularly.

QUALITY STATEMENT 6:
Management of Pain and Other Symptoms

People with identified palliative care needs have their pain and other symptoms managed effectively, in a timely manner.

QUALITY STATEMENT 7:
Psychosocial Aspects of Care

People with identified palliative care needs receive timely psychosocial support to address their mental, emotional, social, cultural, and spiritual needs.

QUALITY STATEMENT 8:
Education for Patients, Substitute Decision-Makers, Families, and Caregivers

People with a progressive, life-limiting illness, their future substitute decision-maker, their family, and their caregivers are offered education about palliative care and information about available resources and supports.

QUALITY STATEMENT 9:
Caregiver Support

Families and caregivers of people with identified palliative care needs are offered ongoing assessment of their needs, and are given access to resources, respite care, and grief and bereavement support, consistent with their preferences.

QUALITY STATEMENT 10:
Transitions in Care

People with identified palliative care needs experience seamless transitions in care that are coordinated effectively among settings and health care providers.

QUALITY STATEMENT 11:
Setting of Care and Place of Death

People with identified palliative care needs, their substitute decision-maker, their family, and their caregivers have ongoing discussions with their health care professionals about their preferred setting of care and place of death.

QUALITY STATEMENT 12:
Interdisciplinary Team-Based Care

People with identified palliative care needs receive integrated care from an interdisciplinary team, which includes volunteers.

QUALITY STATEMENT 13:
Education for Health Care Providers and Volunteers

People receive palliative care from health care providers and volunteers who possess the appropriate knowledge and skills to deliver high-quality palliative care.

1

Identification and Assessment of Needs

People with a progressive, life-limiting illness have their palliative care needs identified early through a comprehensive and holistic assessment.

Background

Palliative care focuses on the person and their family, and on enhancing their quality of life throughout their illness, not just at the end of life.[13,14] The initiation of palliative care should not be delayed for people with a progressive, life-limiting illness if they have physical, psychological, social, or spiritual needs during treatment.

General considerations for identifying people who would benefit from palliative care include the following: diagnosis of a progressive, life-limiting illness; disease progression; functional decline; presence of pain or other symptoms; or other effects on their full range of needs.[15,16] A comprehensive, holistic assessment allows health care professionals to determine the physical, psychological, social, linguistic, cultural, legal, ethical, and spiritual needs of people with a progressive, life-limiting illness and their family or caregivers, and the services required to meet those needs.[15] The initiation of palliative care is not determined by prognosis; it can begin as early as the time of diagnosis of a progressive, life-limiting illness, and it can be initiated during treatment.[15]

BACKGROUND CONTINUED

Assessment can be conducted by any knowledgeable and skilled member of the interdisciplinary health care team (see Quality Statement 4). After the initial assessment, palliative care needs should be reassessed regularly, because they can change over time.

Sources: Institute for Clinical Systems Improvement, 2013[15] | National Institute for Health and Care Excellence, 2015[17] | Registered Nurses' Association of Ontario, 2011[18]

What This Quality Statement Means

For Patients, Families, and Caregivers

Your care team should assess what palliative care or supports you need:

- They should ask questions about your physical and mental health, your support system, and any other needs you feel you have, to understand how best to help you
- They should assess your pain and other health concerns, and manage them quickly and effectively
- They should assess your mental, emotional, social, cultural, and spiritual well-being
- They should ask your family members and caregivers about the help they need

For Clinicians

Assess people with a progressive, life-limiting illness to determine whether they would benefit from palliative care. Perform and document a comprehensive, holistic assessment that considers the individual's diagnosis, disease progression, functional decline, presence of pain or other symptoms, and other effects on their full range of needs. Assessment should be repeated regularly.

For Health Services

Ensure that systems, processes, and resources are in place in all health settings for clinicians to identify and assess people's palliative care needs. This includes access to screening or assessment tools and timely access to palliative care.

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Progressive, life-limiting illness

A progressive, life-limiting illness is one that affects a person's health and quality of life, that gets worse over time, and that can lead to death in the near future.[19] Examples of illnesses that require a palliative approach to care include cancer, Alzheimer disease and other types of dementia, heart failure, chronic obstructive pulmonary disease, kidney disease, and cirrhosis of the liver.[16] The frail elderly can also benefit from a palliative approach to care.

Palliative care needs

Palliative care needs can stem from any part of a person's full range of needs (physical, psychological, social, linguistic, cultural, legal, ethical, or spiritual) at any stage of illness. The goal of palliative care is to help people achieve their best possible quality of life in the face of a progressive, life-limiting illness.

Identified early

Identifying the need for palliative care can occur as early as the time of diagnosis of a progressive, life-limiting illness. Palliative care is not limited to the end-of-life phase, and it is not restricted to specific diseases or conditions.

Quality Indicators

Process Indicators

Percentage of people with identified palliative care needs who have a documented assessment of their palliative care needs including physical, psychological, social, linguistic, cultural, legal, ethical, spiritual, and other needs

- Denominator: total number of people with identified palliative care needs
- Numerator: number of people in the denominator who have a documented assessment of their palliative care needs including physical, psychological, social, linguistic, cultural, legal, ethical, spiritual, and other needs
- Data source: local data collection
- Note: consider measuring separately by each palliative care need and/or grouping them together as an overall measure

Number of days between receiving first palliative care service and death

- Calculation: can be measured as mean, median, or distribution
- Data sources: National Ambulatory Care Reporting System (NACRS), Discharge Abstract Database (DAD), Continuing Care Reporting System (CCRS), Home Care Database (HCD), Ontario Health Insurance Plan (OHIP), Registered Persons Database (RPDB)

Structural Indicator

Evidence of locally adopted tools to:

- **Identify people in need of palliative care**
- **Assess their needs**

- Data source: local data collection

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Comprehensive and holistic assessment

This includes a full examination of the domains of care associated with illness and bereavement, including[18,20]:

- Disease management
- Physical
- Psychological
- Social
- Cultural[15]
- Legal
- Ethical[15]
- Spiritual
- Practical
- End-of-life
- Loss, grief

Examples of validated tools used for assessment may include the Edmonton Symptom Assessment System,[15,18] and the Palliative Performance Scale. The comprehensive and holistic assessment considers a person's socio-cultural context, and initial assessments should include inquiry about a person's mother tongue and language of preference.

2

Timely Access to Palliative Care Support

People with identified palliative care needs have access to palliative care support 24 hours a day, 7 days a week.

Background

People with a progressive, life-limiting illness may have complex needs that require advice, resources, treatment, or support, and those needs may change over time.[21] The needs of people with a progressive, life-limiting illness (and those of their families and caregivers) often arise during the evening, overnight, or on the weekend. Palliative care support should be available whenever the person needs it, at any time of day or night. Appropriate palliative care support is determined based on a person's individual needs and does not necessarily mean continuous, around-the-clock care or services.

The availability of coordinated and integrated palliative care support from a knowledgeable and skilled interdisciplinary care team is important to meet patient, family, and caregiver needs.[21] With education to build capacity, palliative care needs can be addressed by primary care providers through primary-level palliative care (a palliative approach to care). Some complex palliative care needs may require consultation and clinician-to-clinician support (shared care) or may require greater involvement or transfer to specialist palliative care teams. All people, regardless of their diagnosis, prognosis, or location, should be able to access palliative care support appropriate to their needs at any time.

Source: Working group consensus

What This Quality Statement Means

For Patients, Families, and Caregivers

Palliative care support should be available for you whenever you need it, day or night.

For Clinicians

Ensure that people with identified palliative care needs have access to palliative care support 24 hours a day, 7 days a week, as needed.

For Health Services

Ensure that systems, processes, and resources are in place so that people with identified palliative care needs can receive palliative care support whenever they need it, at any time of day or night.

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Palliative care support

Palliative care support consists of health advice, resources, treatment, and other assistance provided by the health care team to meet a person's palliative care needs. Support should be culturally relevant and it can come in many forms, including a telephone call with a registered nurse; a number to call when pain or other symptoms are not well managed; or a home visit from a primary care or palliative care provider.

Quality Indicators

Structural Indicator

Local availability of palliative care support (as defined on the previous page) that is accessible 24 hours a day, 7 days a week

- Data source: local data collection

Outcome Indicator

Percentage of people with identified palliative care needs (or their caregivers) who state that they are able to receive community palliative care support, including after-hours care, when needed

- Denominator: total number of people with identified palliative care needs (or their caregivers)
- Numerator: number of people in the denominator who state that they are able to receive community palliative care support, including after-hours care, when needed
- Data source: local data collection

3

Advance Care Planning—Substitute Decision-Maker

People with a progressive, life-limiting illness know who their future substitute decision-maker is. They engage in ongoing communication with their substitute decision-maker about their wishes, values, and beliefs, so that the substitute decision-maker is empowered to participate in the health care consent process if required.

Background

Advance care planning includes understanding and confirming a future substitute decision-maker who can communicate a person's wishes, values, and beliefs about future health care, and make decisions when that person is no longer mentally capable of doing this for themself. The Ontario *Health Care Consent Act* outlines a hierarchical list of people who would automatically be considered a substitute decision-maker when a person is mentally incapable of making decisions about their own care.[22] If a person is not satisfied with their automatic substitute decision-maker, they can formally appoint someone else to be their substitute decision-maker using a "Power of Attorney for Personal Care."[23] A "Power of Attorney for Personal Care" is a legal document in which one person gives another person the authority to make personal care decisions on their behalf if they become incapable.[1] A "Power of Attorney for Personal Care" is for personal care decisions (e.g., health care, nutrition, safety). Financial and property decisions are made through a "Continuing Power of Attorney for Property."

BACKGROUND CONTINUED

Ongoing communication between the person with a progressive, life-limiting illness and their substitute decision-maker is important so that the substitute decision-maker is aware of their role and can participate fully as the decision-maker for the person if or when they are no longer able to communicate. The substitute decision-maker follows the person's wishes where they are known, and acts in the person's best interests if no wishes are known or applicable to the decision to be made.[15] Advance care planning is relevant for every person and family, and these conversations should take place in health and illness. Advance care planning should be revisited regularly as a person's condition changes.

Sources: Institute for Clinical Systems Improvement, 2013[15] | National Institute for Health and Care Excellence, 2015[17] | Ontario Health Technology Advisory Committee, 2014[24]

What This Quality Statement Means

For Patients, Families, and Caregivers

Make sure you know who your future substitute decision-maker will be, by Ontario law, if you become mentally incapable of making health decisions. Ontario's *Health Care Consent Act* automatically assigns a substitute decision-maker based on a ranked list.

If the person Ontario's *Health Care Consent Act* automatically assigns to be your substitute decision-maker is not the person you want in this role, prepare a legal document called a "Power of Attorney for Personal Care." It is not enough to tell your care team that you want a different substitute decision-maker.

Once you have confirmed your substitute decision-maker, talk with them regularly about your wishes, values, and beliefs. This will help them make the right decisions for you, if needed. If your wishes change, keep them informed.

For Clinicians

Ensure that your patients know who the law considers to be their substitute decision-maker(s) and how they can appoint someone else if they wish. Encourage patients to plan for their care—to think about their values, wishes, and beliefs, and then share those with their family and their substitute decision-maker.

For Health Services

Ensure that information and resources are available for people to learn about Ontario laws related to advance care planning, substitute decision-making, and health care consent.

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Advance care planning

Advance care planning is ongoing and dynamic, because a person's preferences may change over time as their health changes.[1] It may be initiated at any point, and may involve people who are currently healthy. In advance care planning, a mentally capable person identifies their substitute decision-maker by confirming the automatic substitute decision-maker from the hierarchy list in the *Health Care Consent Act** or by choosing someone else using a "Power of Attorney for Personal Care."[22] The hierarchy outlined in Ontario's *Health Care Consent Act* is as follows (note: numbers 1 to 3 occur if people are legally appointed to these roles):

1. Guardian of the person with authority for health decisions
2. Attorney for personal care with authority for health decisions
3. Representative appointed by the Consent and Capacity Board
4. Spouse or partner
5. Child or parent or a children's aid society (person with right of custody)
6. Parent with right of access
7. Brother or sister
8. Any other relative
9. Office of the Public Guardian and Trustee

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Quality Indicators

Process Indicators

Percentage of people with identified palliative care needs who know who their future substitute decision-maker is

- Denominator: total number of people with identified palliative care needs
- Numerator: number of people in the denominator who know who their future substitute decision-maker is
- Data source: local data collection
- Similar question available in the CaregiverVoice Survey: "Did your family member/friend know which person would be their substitute decision-maker in case he/she was not able to make decisions about future care?" (Response options: "Yes, he/she knew who their substitute decision-maker would be; No, he/she did not know who their substitute decision-maker would be; Don't know")[11,12]

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Advance care planning (continued)

The capable person then shares their wishes, values, and beliefs with the substitute decision-maker, and discusses how they would like to be cared for if they become mentally incapable of giving or refusing consent.

*https://www.ontario.ca/laws/statute/96h02#BK25

Substitute decision-maker

A substitute decision-maker is a person who makes care and treatment decisions on another person's behalf if or when that person becomes mentally incapable of making decisions for themselves.[1] The substitute decision-maker makes decisions based on their understanding of the person's wishes, or, if these are unknown or not applicable, makes choices that are consistent with the person's known values and beliefs and in their best interests.

Wishes, values, and beliefs

A person's wishes, values, and beliefs convey who the person is, how they would make choices for themselves, what they think is important, and what would influence their decision-making.[19,25] Values are the principles on which a person's morality and/or spirituality is based. If a person is mentally incapable of making choices for themselves, the substitute decision-maker (not the health care professional) interprets their wishes.

PROCESS INDICATORS CONTINUED

Percentage of people with identified palliative care needs who state that they have shared their wishes, values, and beliefs with their substitute decision-maker regarding the kind of health and personal care they would want to receive in the future

- Denominator: total number of people with identified palliative care needs who know who their substitute decision-maker is
- Numerator: number of people in the denominator who state that they have shared their wishes, values, and beliefs with their substitute decision-maker regarding the kind of health and personal care they would want to receive in the future
- Data source: local data collection
- Similar question available in the CaregiverVoice Survey: "Did he/she have conversations with his/her substitute decision-maker to share their wishes, values, and beliefs about the kind of health and personal care they would want to receive in the future?" (Response options: "Yes, he/she had these conversations with their substitute decision-maker; No, he/she did not have these conversations with their substitute decision-maker; Don't know")[11,12]

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Health care consent

Health care consent refers to an informed and contextualized decision involving a mentally capable person and a health care provider as outlined in the Ontario *Health Care Consent Act*.[22] Health care providers who propose a treatment must obtain informed consent from a mentally capable patient (or their substitute decision-maker, if they do not have the mental capacity). A discussion about consent must address the person's present condition; available treatment options; risks, benefits, side effects, and alternatives to treatment; and what would happen without the proposed treatment.[1]

Capacity or mental capacity

Under Ontario's *Health Care Consent Act*, a person is capable with respect to a health care decision if they have the ability to understand the information that is needed to make a decision and have the ability to appreciate the consequences of the decision or lack of decision.[1,22] Capacity is issue- or task-specific.[26] A person's specific capacity to understand information and appreciate the decisions that must be made should be respected so that their mental capacity for a specific health care decision is recognized.[26] A person may be capable with respect to making some health care decisions, but incapable with respect to others.[22] If a person is incapable with respect to making a health care decision, the substitute decision-maker can give or refuse consent on the person's behalf.[22]

4

Goals of Care Discussions and Consent

People with identified palliative care needs or their substitute decision-makers have discussions with their interdisciplinary health care team about their goals of care to help inform their health care decisions. These values-based discussions focus on ensuring an accurate understanding of both the illness and treatment options so the person or their substitute decision-maker has the information they need to give or refuse consent to treatment.

Background

People with a progressive, life-limiting illness (and/or their substitute decision-maker) should have discussions with their interdisciplinary health care team to address the person's goals of care, obtain health care consent, and inform decision-making when illness is advanced.[1] The purposes of discussions about goals of care are to ensure that the person (or their substitute decision-maker, if the person is incapable) understands the serious nature of their illness, and to help the health care team understand the person's values and goals for their care. These discussions are intended to elicit what the patient wants to achieve as a result of treatment or care that may be provided to them, and to help prepare the patient and the provider to engage in subsequent decision-making and the consent process. Goals of care discussions will often lead to the development of a plan of treatment and a care plan (see Quality Statement 5); however, they do not constitute consent to treatment.

BACKGROUND CONTINUED

Informed consent must be obtained from the person or substitute decision-maker for any treatment or plan of treatment.[15] A plan of treatment is developed by one or more health care professionals. It deals with one or more health problems, provides for the administration of various treatments or courses of treatments, and may provide for the withholding and withdrawal of treatment in light of the person's current health condition. When individuals lack the capacity to make decisions, health care professionals must work with substitute decision-makers to determine an appropriate course of action.

Sources: Institute for Clinical Systems Improvement, 2013[15] | Ontario Health Technology Advisory Committee, 2014[24]

What This Quality Statement Means

For Patients, Family, and Caregivers

Your care team should talk with you about your illness and how it could progress. They should also talk with you about your values and goals and your treatment options. These discussions will help you understand your illness, your goals of care, and your treatment options so you can make decisions about your care and provide health care consent.

For Clinicians

Talk to your patients about their illness, prognosis, goals of care, and treatment options. Ongoing discussions are beneficial for ensuring that patients' values, beliefs, and wishes are aligned with the care provided. Providing information to help the patient or their substitute decision-maker provide informed consent and getting informed consent before providing treatment is your legal and ethical duty.

For Health Services

Ensure that health care professionals are given adequate education and training so they feel equipped to have meaningful conversations with their patients about their illness, prognosis, goals of care, and treatment options and to fulfil their duty to obtain informed consent

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Substitute decision-maker

A substitute decision-maker is a person who makes care and treatment decisions on another person's behalf if or when that person becomes mentally incapable of making decisions for themselves.[1] The substitute decision-maker makes decisions based on their understanding of the person's wishes, or, if these are unknown or not applicable, makes choices that are consistent with the person's known values and beliefs and in their best interests.

Family

Family consists of those closest to a person in terms of knowledge, care, and affection, and may include biological family, family through marriage, or family of choice and friends.[19] The person with the progressive, life-limiting illness defines their family and who will be involved in their care.

Caregiver

A caregiver is an unpaid person who provides care and support in a nonprofessional capacity, such as a family member, a friend, or anyone else identified by the person with a progressive, life-limiting illness. Other terms commonly used to describe this role include care partner, informal caregiver, family caregiver, carer, or primary caregiver.

Quality Indicators

Process Indicator

Percentage of people with identified palliative care needs who have documented discussions with a health care professional about their goals of care in their medical record

- Denominator: total number of people with identified palliative care needs
- Numerator: number of people in the denominator who have documented discussions with a health care professional about their goals of care in their medical record
- Data source: local data collection

Outcome Indicators

Percentage of people with identified palliative care needs (or their caregivers) who state that discussions with a health care professional about their goals of care helped them to make treatment decisions

- Denominator: total number of people with identified palliative care needs (or their caregivers) who had discussions with a health care professional about their goals of care
- Numerator: number of people in the denominator who state that those discussions helped them to make treatment decisions
- Data source: local data collection

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Goals of care

A person's goals of care are their overall priorities and health expectations for care; these are based on their personal values, wishes, beliefs, and perception of quality of life, and what they characterize as meaningful and important.[1] Examples of goals of care could be curing the disease, prolonging life, relieving suffering, optimizing quality of life, maintaining control, achieving a good death, and getting support for family and loved ones.[27] Goals of care are not the same as health care decisions or consents for treatments.

Interdisciplinary health care team

An interdisciplinary health care team consists of two or more people with different types of training and skills who work together to provide care based on a person's care plan (see Quality Statement 5).[19] The composition of the team varies depending on the services needed. The team may include various roles, as needed: physicians, nurse practitioners, registered nurses, registered practical nurses, social workers, psychologists, spiritual care providers, pharmacists, personal support workers, dietitians, and volunteers.

OUTCOME INDICATORS CONTINUED

Percentage of people with identified palliative care needs (or their caregivers) who state that discussions about goals of care with a health care professional happened at the right time

- Denominator: total number of people with identified palliative care needs (or their caregivers) who indicate that they had goals of care discussion
- Numerator: number of people in the denominator who state that goals of care discussions happened at the right time
- Data source: local data collection
- Similar questions available in the CaregiverVoice Survey:
  - "Who introduced the conversation about his/her values and wishes for the kind of health and personal care they would want to receive in the future?" (Response options: "Family or friend; His/her family doctor; Palliative care doctor; Nurse practitioner; Oncologist; Other doctor/specialist; Homecare nurse; Hospital nurse; Hospice nurse; Other; Don't know; This conversation didn't happen")[11,12]
  - "Did this conversation happen:" (Response options: "Too early; Too late; At the right time; Don't know")[11,12]

Percentage of people receiving palliative care whose informed consent (obtained directly or from the substitute decision-maker) is documented prior to the initiation of a treatment

- Denominator: total number of people who receive palliative care
- Numerator: number of people in the denominator whose informed consent (obtained directly or from the substitute decision-maker) is documented prior to initiation of a treatment
- Data source: local data collection

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Consent to treatment

Consent to treatment (health care consent) refers to an informed decision involving a mentally capable person or their substitute decision-maker and a health care provider as outlined in the Ontario *Health Care Consent Act*. Health care providers proposing treatment must obtain informed consent from either a capable person or their substitute decision-maker if they do not have the mental capacity. This discussion must address present condition (context), available treatment options, risks, benefits, side effects, alternatives to treatment and what would happen without the proposed treatment.

5

Individualized, Person-Centred Care Plan

People with identified palliative care needs collaborate with their primary care provider and other health care professionals to develop an individualized, person-centred care plan that is reviewed and updated regularly.

Background

Creating and documenting an individualized, person-centred care plan improves the quality and efficiency of care.[28] Care plans place the patient at the focal point and guide the care that is provided. The use of care plans promotes communication, continuity of care, and coordination of care.[28] The care plan should include the person's goals and wishes, treatment decisions and consents to treatments or plan of treatment, preferred care setting, current and anticipated care needs, and the resources required to meet those needs.[17] The care plan is documented in the medical record so that all team members have access to the information.[17] The care plan is shared with the patient or their substitute decision-maker. The person's ability to be involved in making decisions may change as their condition changes, and the care plan should be updated accordingly.[17]

Source: National Institute for Health and Care Excellence, 2015[17]

What This Quality Statement Means

For Patients, Families, and Caregivers

Your care team should work with you to create a care plan that fits your values, wishes, and goals. Your care team should use this plan to provide palliative care that meets your needs. This care plan should be updated as often as you need.

For Clinicians

Collaborate with people with identified palliative care needs to create and document a care plan that reflects their individual values, wishes, and goals of care. This plan should be created at the start of their care and then reviewed and updated as needed.

For Health Services

Ensure that all health care settings have the tools, systems, processes, and resources in place for health care professionals and people with identified palliative care needs to create, document, and share individualized, person-centred care plans.

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Individualized, person-centred care

Individualized, person-centred care consists of care and treatment that is customized for each person based on their values, wishes, goals, and unique health needs.[29] The person with the progressive, life-limiting illness drives the care provided; a person-centred approach involves a partnership between patients and their health care professionals.

Care plan

A care plan is a written document that describes a person's health needs and goals and the care that will be provided to meet them.[1,19] A care plan is not the same as having a discussion about goals of care. Nor is it a decision or consent for treatments. A care plan is broader and different than a plan of treatment. A plan of treatment is associated with a health care decision and requires informed consent from the patient or substitute decision-maker.

Quality Indicators

Process Indicators

Percentage of people with identified palliative care needs (or their caregivers) who state that they worked together with their health care provider to develop a care plan

- Denominator: total number of people with identified palliative care needs (or their caregivers)
- Numerator: number of people in the denominator who state that they worked together with their health care provider to develop a care plan
- Data source: local data collection

Percentage of people with identified palliative care needs (or their caregivers) who state that they have had the opportunity to review and update their care plan when they wanted to do so

- Denominator: total number of people with identified palliative care needs (or their caregivers) who have a care plan
- Numerator: number of people in the denominator who state that they have had the opportunity to review and update their care plan when they wanted to do so
- Data source: local data collection

Outcome Indicator

Percentage of people with identified palliative care needs who have a documented care plan in their medical record

- Denominator: total number of people with identified palliative care needs
- Numerator: number of people in the denominator who have a documented care plan in their medical record
- Data source: local data collection

6

Management of Pain and Other Symptoms

People with identified palliative care needs have their pain and other symptoms managed effectively, in a timely manner.

Background

Management of pain and other symptoms is an important part of high-quality palliative care and an integral component of the individualized care plan.[15,17] It is important to consider nonpharmacological and pharmacological management throughout a person's illness.

Not all patients who receive palliative care will experience the same pain or other symptoms, so it is important to assess the level and range of severity. Possible causes of symptoms, the person's preferences, management of side effects, and the benefits and harms of intervention should also be assessed. If pain or other symptoms are identified, they should be managed promptly and effectively, and any reversible causes should be treated using evidence-based practice.[17]

An example of pain and symptom management in the community involves the use of "symptom relief kits," which are standardized kits designed to provide the nurse and patient with a supply of commonly used palliative care medications.[30-33] Pain and symptom management require ongoing reassessment to ensure the efficacy of any interventions and monitoring for changes.[17]

Sources: Institute for Clinical Systems Improvement, 2013[15] | National Institute for Health and Care Excellence, 2015[17] | Registered Nurses' Association of Ontario, 2011[18]

What This Quality Statement Means

For Patients, Families, and Caregivers

Your health care team should assess your pain and other health concerns, and manage them quickly and effectively.

For Clinicians

Assess patients for pain and other symptoms. Ensure the delivery of high-quality management of pain and other symptoms.

For Health Services

Provide adequately resourced systems and services to ensure that health care professionals can conduct pain and symptom assessments and offer nonpharmacological and pharmacological treatments. Ensure that systems, processes, and resources are in place so that patients have access to timely and effective pain and symptom management.

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Pain and other symptoms

Pain and other symptoms are the effects of illness or treatment. Common symptoms associated with progressive, life-limiting illness may include but are not limited to the following:

- Agitation[17]
- Anxiety[15,18]
- Changes in respiratory patterns and increased secretions[17]
- Constipation[18]
- Dehydration[17]
- Delirium[17,18]
- Depression[15]
- Diarrhea
- Dyspnea[17,18]
- Fatigue
- Nausea[17,18]
- Pain[15,17,18]
- Poor appetite
- Vomiting[17,18]

Pain and other symptoms can also affect activities of daily living (e.g., bathing, mobility, continence).

Quality Indicators

Process Indicator

Percentage of people who receive palliative care who have documented assessments of their pain and other symptoms in their medical record

- Denominator: total number of people who receive palliative care
- Numerator: number of people in the denominator who have documented assessments of their pain and other symptoms in their medical record
- Data source: local data collection

Structural Indicator

Locally adopted appropriate tools to assess pain and other symptoms for people with identified palliative care needs

- Data source: local data collection

Outcome Indicator

Percentage of people who receive palliative care (or their caregivers) who rate the level of support to relieve their pain and other symptoms as excellent

- Denominator: total number of people who receive palliative care (or their caregivers)
- Numerator: number of people in the denominator who rate the level of support to relieve their pain and other symptoms as excellent
- Data sources: local data collection; alternative source is InterRAI [Resident Assessment Instrument] tools
- Similar question available in the CaregiverVoice Survey: "During the last 3 months of his/her life, while he/she was receiving homecare services, what is your assessment of the overall level of support given in the following areas: relief of physical pain, relief of other symptoms?" (Response options: "Excellent, Very good, Good, Fair, Poor, Does not apply, Don't know")[11,12]

7

Psychosocial Aspects of Care

People with identified palliative care needs receive timely psychosocial support to address their mental, emotional, social, cultural, and spiritual needs.

Background

When people face a progressive, life-limiting illness, psychosocial issues may go undetected or untreated, and this can affect their quality of life.[15] Pain and other symptoms may be the initial focus of treatment, but psychosocial well-being should also be assessed regularly. A holistic psychosocial assessment can facilitate the identification of any supports a person needs during their illness.

Psychosocial issues can manifest as physical symptoms (e.g., pain, constipation, nausea). Therefore, it is important that health care professionals be aware of a person's total pain and the physiological symptoms that may be an indication of depression and anxiety.[15] The concept of total pain describes the suffering that expands beyond physical pain by encompassing all of a person's physical, psychological, social, spiritual, and practical struggles.[18]

Illness and the prospect of dying affect and can also be affected by the meaning and purpose of a person's life. A focus on spirituality may include questions about meaning, value, and relationships, and can lead to spiritual concerns, questions, or distress. Patients may draw on their spirituality as they make health care decisions and as they cope with illness and the experience of dying.[15] No single individual is responsible for addressing all psychosocial needs; rather, it requires expertise from an interdisciplinary team.

Sources: Institute for Clinical Systems Improvement, 2013[15] | Registered Nurses' Association of Ontario, 2011[18]

What This Quality Statement Means

For Patients, Families, and Caregivers

Your care team should assess your mental, emotional, social, cultural, and spiritual well-being. Your needs should be addressed as part of your care plan and according to your wishes, values, and goals of care.

For Clinicians

Ensure that the overall psychosocial well-being of people with identified palliative care needs is assessed, and that their needs are incorporated into the care plan.

For Health Services

Ensure that resources are available for health care professionals to assess and meet the psychosocial needs of people with identified palliative care needs.

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Psychosocial support

Psychosocial support involves care related to a person's state of mental, emotional, social, cultural, and spiritual well-being.[15,18]

Mental and emotional needs

Mental and emotional needs relate to a person's psychological and emotional well-being. Issues of concern for a person with a progressive, life-limiting illness may include fear, worry, insomnia, panic, anxiety, nervousness, paranoia, or lack of energy.[18]

Quality Indicators

Process Indicators

Percentage of people who receive palliative care who have assessments of their psychosocial needs documented in their medical record

- Denominator: total number of people who receive palliative care
- Numerator: number of people in the denominator who have assessments of their psychosocial needs documented in their medical record
- Data source: local data collection

Percentage of people who receive palliative care (or their caregivers) who state that they received timely psychosocial support to address their identified mental, emotional, social, cultural, and spiritual needs

- Denominator: total number of people who receive palliative care who had identified psychosocial needs (or their caregivers)
- Numerator: number of people in the denominator who state that they received timely psychosocial support to address their mental, emotional, social, cultural, and spiritual needs
- Data source: local data collection
- Note: consider measuring separately by each type of psychosocial need or group together as an overall measure of psychosocial support

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Social needs

Social needs relate to a person's relationships with their family, community, and network (friends, acquaintances, and coworkers).[15] Social needs may relate to family structure and location, family dynamics, communication, social and cultural networks, perceived social support, work and school settings, finances, sexuality, intimacy, living arrangements, caregiver availability, medical decision-making, access to transportation, medications, equipment and nutrition, community resources, or legal issues. Associated practical needs include pet care, child care, transportation, or meals.

Cultural needs

Cultural needs relate to the beliefs and preferences that come from one's social and ethnic identity. Cultural needs may include linguistic needs, health beliefs and behaviours, traditions, rituals, or cultural barriers to accessing health care.

Outcome Indicator

Percentage of people who receive palliative care (or their caregivers) who rated the level of support in addressing their psychosocial needs (mental, emotional, social, cultural, and spiritual) as excellent

- Denominator: total number of people who receive palliative care with psychosocial needs (or their caregivers)
- Numerator: number of people in the denominator who rated the level of support in addressing their psychosocial needs (mental, emotional, social, cultural, and spiritual) as excellent
- Data source: local data collection
- Similar question available in the CaregiverVoice Survey: "During the last 3 months of his/her life, while he/she was receiving homecare services, what is your assessment of the overall level of support given in the following areas: spiritual support, emotional support, respect and dignity?" (Response options: "Excellent, Very good, Good, Fair, Poor, Does not apply, Don't know")[11,12]
- Note: consider measuring separately by each type of psychosocial need or group together as an overall measure of psychosocial support

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Spiritual needs

Spiritual needs relate to "the way individuals seek and express meaning and purpose, and the way they experience their connection to the moment, to self, to others, to nature, and to the significant or sacred."[15] Spiritual needs may include religious practices or philosophical reflection.

8

Education for Patients, Substitute Decision-Makers, Families, and Caregivers

People with a progressive, life-limiting illness, their future substitute decision-maker, their family, and their caregivers are offered education about palliative care and information about available resources and supports.

Background

For people with a progressive, life-limiting illness, their substitute decision-makers, and their family and caregivers, education plays a vital role in increasing their knowledge about their care, providing reasonable expectations about illness progression and palliative care, and preparing them for the decisions they will need to make.[18,34] Education can increase a person's sense of self-control and well-being.[34] Education about symptom management and coping strategies improves symptom control for patients at the end of life and improves quality of life for caregivers.[24] It is important that the education provided is sensitive to health literacy and linguistic and cultural preferences. The information can be delivered in a variety of formats, from in-person interaction to using written materials, online self-training, or hands-on skills practice and problem-solving.[34]

Sources: Ontario Health Technology Advisory Committee, 2014[24] | Registered Nurses' Association of Ontario, 2011[18]

What This Quality Statement Means

For Patients, Families, and Caregivers

Your care team should give you, your family, your substitute decision-maker, and your caregivers information about palliative care. They should also give you information about resources and supports, such as counselling, hospice volunteers, wellness programs, spiritual care, or support groups. This knowledge can help you understand your treatment and service options, how palliative care can improve your quality of life, and how to connect with available supports.

For Clinicians

Provide education about palliative care to patients, their families, and their caregivers, and offer information about available resources and supports.

For Health Services

Ensure that educational resources and tools about palliative care are available for health care professionals, patients, their families, and their caregivers.

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Education

Education topics may include symptom management, grief and loss, coping strategies, available community resources, system navigation, patient rights, health decision-making, medication, practical and physical care, death and dying, vigil practices, and care after death.[18,34,35]

Quality Indicators

Process Indicators

Percentage of people with identified palliative care needs (or their caregivers) who state that health care professionals helped them understand palliative care and provided information about available resources and supports

- Denominator: total number of people with identified palliative care needs (or their caregivers)
- Numerator: number of people in the denominator who state that health care professionals helped them understand palliative care and provided information about available resources and supports
- Data source: local data collection

PROCESS INDICATORS CONTINUED

Percentage of people with identified palliative care needs (or their caregivers) who state that a health care professional helped them understand what to expect and how to prepare for each stage of the journey toward the end of life

- Denominator: total number of caregivers of people with identified palliative care needs (or their caregivers)
- Numerator: number of people in the denominator who state that health care professionals helped them understand what to expect and how to prepare for each stage of the journey toward the end of life
- Data source: local data collection
- Similar question available in the CaregiverVoice Survey: "Did your healthcare providers help you, the caregiver, understand what to expect/how to prepare for his/her death?" (Response options: "Yes; No, I was not aware of these services but I would have liked to use them; No, I was not aware of these services but I was not interested anyway; No, I was aware of these services but I was not interested anyway; Not sure")[11,12]

Structural Indicator

Local availability of resources and tools for health care professionals to provide education about palliative care to patients, families, and caregivers

- Data source: local data collection

9

Caregiver Support

Families and caregivers of people with identified palliative care needs are offered ongoing assessment of their needs, and are given access to resources, respite care, and grief and bereavement support, consistent with their preferences.

Background

Families and caregivers of people with a progressive, life-limiting illness have needs across multiple domains. Families and caregivers benefit from support as they manage medical information, learn how to provide care, and develop coping strategies to deal with medical care, personal care, psychosocial care, loss, grief, and bereavement. General advice and support, along with education to improve coping and communication skills for caregivers, are associated with decreased distress.[24]

Source: Working group consensus

9

Caregiver Support

What This Quality Statement Means

For Patients, Families, and Caregivers

Caregiving can be a rewarding experience, but it can also be stressful. If you are a caregiver, a member of the care team should assess you to see how you are coping and help you get the supports you need. Supports can include training, support groups, home care, and temporary respite care for the person you are caring for. Respite care can give you a break from the caregiving routine and give you time to take care of yourself.

For Clinicians

Offer assessment and appropriate support to the family and caregivers of people with identified palliative care needs.

For Health Services

Ensure that systems are in place to offer assessment and appropriate support to the family and caregivers of people with identified palliative care needs.

Quality Indicators

Process Indicators

Percentage of people with identified palliative care needs who have a caregiver needs assessment documented in their medical record

- Denominator: total number of people with identified palliative care needs who have a caregiver
- Numerator: number of people in the denominator who have a caregiver needs assessment in their medical record
- Data source: local data collection

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Family

Family consists of those closest to a person in terms of knowledge, care, and affection, and may include biological family, family through marriage, or family of choice and friends.[19] The person with the progressive, life-limiting illness defines their family and who will be involved in their care.

Caregiver

A caregiver is an unpaid person who provides care and support in a nonprofessional capacity, such as a family member, a friend, or anyone else identified by the person with a progressive, life-limiting illness. Other terms commonly used to describe this role include care partner, informal caregiver, family caregiver, carer, or primary caregiver.

PROCESS INDICATORS CONTINUED

Percentage of caregivers of people who receive palliative care who state that they and their family members receive as much help and support as they need

- Denominator: total number of caregivers of people who receive palliative care
- Numerator: number of people in the denominator who state that they and their family members receive as much help and support as they need
- Data source: local data collection
- Similar question available in the CaregiverVoice Survey: "Overall, do you feel that you and your family got as much help and support from homecare services as you needed?" (Response options: "Yes, we got as much support as we needed; No, we did not get as much support as we needed though we tried to get more; No, we did not get as much support as we needed, but we did not ask for more")[11,12]

Percentage of caregivers who state that, after the patient's death, they talked to someone from health and supportive services or bereavement services about their feelings regarding the illness and death

- Denominator: total number of caregivers of people who died of a progressive, life-limiting illness
- Numerator: number of people in the denominator who state that, after the patient's death, they talked to someone from health and supportive services or bereavement services about their feelings regarding the illness and death
- Data source: local data collection
- Similar question available in the CaregiverVoice Survey: "Since he/she died, have you talked to anyone from health and supportive services, or from a bereavement service, about your feelings about his/her illness and death?" (Response options: "Yes; No, I was not aware of these services but I would have liked to use them; No, I was not aware of these services but I was not interested anyway; No, I was aware of these services but I was not interested anyway; Not sure")[11,12]

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Caregiver assessment

A caregiver assessment includes an examination of physical, psychological, social, spiritual, linguistic, cultural, and environmental considerations.[19] The assessment may relate to the caregiver's needs and preferences, as well as associated treatment, care, and support. Use of validated tools may help clinicians explore the caregiver's values and preferences, well-being, burden, skills and abilities, and resources.[18]

10

Transitions in Care

People with identified palliative care needs experience seamless transitions in care that are coordinated effectively among settings and health care providers.

Background

Transitions in care that are based on patient needs involve logistical arrangements to move a person from one care setting to another or from one care provider to another.[36] To ensure continuity of care, transitions in care should be coordinated among knowledgeable and skilled health care professionals who are familiar with the person's clinical status, goals of care, plan of treatment, care plan, and health information needs.[36]

Timely and effective communication is essential to prevent problems that may occur if services and supports are not well integrated (e.g., delayed transfers, readmissions, or poor care).[37] Identifying a member of the care team to be accountable for care coordination supports a smooth transition between settings and prevents communication failures.[37] Information-sharing between settings to ensure all health care providers are aware of the person's current condition is part of effective and coordinated communication. All information-sharing during care transitions must consider legislated privacy and security requirements.[36]

Families and caregivers also play a vital role in transitions. Health care professionals should have informed discussions with them about available care settings. Health care professionals should work together, and with the patient, their family and their caregivers, to ensure that transitions in care are timely, appropriate, and safe.

Source: Working group consensus

What This Quality Statement Means

For Patients, Families, and Caregivers

When you change care settings or care providers (for example, if you return home after being in hospital), your care team should work with you to make sure you and any new team members have the right information (such as information about your medication). They should also make sure you receive the services you need (such as plans for follow-up).

For Clinicians

Ensure that people moving between care settings or care providers experience coordinated and seamless transitions. This includes facilitating communication between settings and other related processes.

For Health Services

Ensure that systems, processes, and resources are in place to facilitate communication and information-sharing between care providers and care settings during transitions.

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Seamless transition

A seamless transition consists of a set of actions designed to ensure the safe and effective coordination and continuity of care when patients experience a change in health status, health care professional, or location (within, between, or across settings).[36,38]

Coordinated effectively

Coordinated care is the deliberate organization of patient care activities between two or more participants involved in a patient's care (including the patient) to facilitate the appropriate delivery of health care services. Organizing care involves coordinating people and resources to carry out required patient care activities and is often managed by exchanging information among those responsible for the various aspects of a patient's care.[36,38]

Quality Indicators

Process Indicator

Percentage of people who receive palliative care whose medical record identifies the member of the care team responsible for care coordination

- Denominator: total number of people who receive palliative care
- Numerator: number of people in the denominator whose medical record identifies the member of care team responsible for care coordination
- Data source: local data collection

Outcome Indicator

Percentage of people who receive palliative care (or their caregivers) who state that they experienced seamless transitions between care settings

- Denominator: total number of people who receive palliative care (or their caregivers)
- Numerator: number of people in the denominator who state that they experienced seamless transitions between care settings
- Data source: local data collection
- Similar question available in the CaregiverVoice Survey: "To what extent did he/she experience smooth transitions between all settings of care during the last 3 months of life?" (Response options: "Always, Most of the time, Sometimes, Rarely, Never, Don't know")[11,12]

11

Setting of Care and Place of Death

People with identified palliative care needs, their substitute decision-maker, their family, and their caregivers have ongoing discussions with their health care professionals about their preferred setting of care and place of death.

Background

A person's preferences for where to receive palliative care and where to die depend on an interplay of factors associated with the illness, the individual, and the environment. A person's preferred setting of care and place of death should be part of a care plan (see Quality Statement 5) that reflects the person's wishes, goals, and needs. Different care settings and places of death are considered, including the person's home (usual place of residence), a long-term care home, a hospice residence, or an in-patient palliative care unit.

Safety is a key consideration when discussing the setting of care and place of death. A number of factors increase the feasibility and likelihood of a home death, including the availability of interdisciplinary home palliative care, early referral to palliative care, patient preferences, having a caregiver, and the caregiver's ability to cope.[24] Discussions about the setting of care and place of death should be ongoing; a person's choice may change depending on their status.

Sources: National Institute for Health and Care Excellence, 2015[17] | Ontario Health Technology Advisory Committee, 2014[24]

What This Quality Statement Means

For Patients, Families, and Caregivers

Your care team should talk with you about where you would like to be cared for throughout your illness and at end of life (for example, at home, in a home-like environment called a hospice residence, in a hospital, or in a long-term care home). They should give you information about the care available in different locations to help you make the best choices for you, your family, and your caregivers. Your wishes may change over time, so you should have regular opportunities to discuss them. You may want to talk about:

- Your preferences
- How your disease affects your ability to perform normal daily activities
- Whether you are living with someone who can help you
- Whether other help you may need is available

For Clinicians

Provide information about options for the setting of care and place of death to people with identified palliative care needs, their family, and their caregivers. This information should include all of the factors outlined in the definitions.

For Health Services

Ensure that resources and tools are available to support discussions between health care professionals and people with identified palliative care needs about their preferred setting of care and place of death.

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Setting of care

The setting of care is the place where palliative care is provided.[19] Care settings may include the person's home, a hospice residence or in-patient palliative care unit, a long-term care home, a correctional facility, or for a person who is homeless or vulnerably housed, a shelter or the street.

Preferred setting of care and place of death

Discussions with health care professionals about the setting of care and place of death should include the following[24]:

- Interdisciplinary palliative care in the person's current place of residence
- Time between referral to palliative care services and death
- Type of underlying disease
- Functional status
- Frequency of hospitalizations during the last year of life
- Living arrangements (e.g., living with someone, living alone)
- Presence of a caregiver
- Caregiver's ability to cope

Quality Indicators

Process Indicator

Percentage of people with identified palliative care needs who have documentation of their preferred setting of care and place of death in their medical record

- Denominator: total number of people with identified palliative care needs
- Numerator: number of people in the denominator who have documentation of their preferred setting of care and place of death in their medical record
- Data source: local data collection
- Similar questions available in the CaregiverVoice survey:
  - "What was his/her last known preferred place to die?" (Response options: "At home; In a hospice; In a hospital; In a long-term care home; In a retirement home; He/she said that he/she did not mind where he/she died; Anywhere except at home; Anywhere except in hospital; Don't know")[11,12]
  - "Did the health care providers have a record of this preference of where he/she wanted to die?" (Response options: "Yes; No; Not sure")[11,12]
- Note: consider measuring the preferred setting of care and preferred place of death separately

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Preferred setting of care and place of death (continued)

- Patient or family preference for place of death
- Consideration of previous advance care planning conversations
- Availability of a long-term care home, hospital bed, or hospice residence bed
- Availability of resources to support the patient's physical and psychological needs, where they live, during the end-of-life period

11

Setting of Care and Place of Death

Structural Indicator

Availability of a survey to capture caregiver experience in all care settings (e.g., CaregiverVoice Survey)

- Data source: local data collection

Outcome Indicators

Percentage of people with identified palliative care needs whose medical records indicate that they died in their preferred place of death

- Denominator: total number of people with identified palliative care needs who had their preferred place of death recorded in their care plan
- Numerator: number of people in the denominator who died in their preferred place of death
- Data source: local data collection (similar indicator is currently measured in the Client Health and Related Information System for palliative home care clients)

Percentage of caregivers of people who died of a progressive, life-limiting illness who think that the person they cared for died in the right place

- Denominator: total number of caregivers of people who died of a progressive, life-limiting illness
- Numerator: number of people in the denominator who think that the person they cared for died in the right place
- Data source: local data collection
- Similar question available in the CaregiverVoice Survey: "Do you think that he/she died in the right place?" (Response options: "Yes; No; Not sure")[11,12]

12

Interdisciplinary Team-Based Care

People with identified palliative care needs receive integrated care from an interdisciplinary team, which includes volunteers.

Background

The model of care used to deliver health services can affect the quality of the care received. Team-based, integrated care facilitates continuity for people with a progressive, life-limiting illness, their family, and their caregivers.[18] The team-based model of care includes the patient, family, and a nurse or physician with the knowledge and skills to deliver palliative care.[24] The team may also include people in other roles, such as social workers, psychologists, spiritual advisors, personal support workers, healers, medicine people, Elders, or volunteers. The services provided by the team include symptom management, psychosocial care, care plan development, advance care planning conversations, goals of care discussions, and care coordination.[24]

Sources: Working group consensus | Ontario Health Technology Advisory Committee, 2014[24]

What This Quality Statement Means

For Patients, Families, and Caregivers

You should have access to care providers who are knowledgeable about palliative care and who will work together to meet your needs and goals of care.

For Clinicians

Collaborate with other health care providers, volunteers, family, and caregivers to meet the needs of people receiving palliative care.

For Health Services

Provide adequately resourced systems and services to ensure that health care professionals, volunteers, and caregivers can work in teams to provide integrated palliative care.

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Integrated care

Health services are managed and delivered so that people receive care that is coordinated across the health system, at all levels and settings, and according to the patient's needs throughout their life course.[39] Integrated care involves the delivery, management, and organization of services for diagnosis, treatment, care, rehabilitation, and health promotion. Integration of care brings about better access, quality, user experience, and efficiency.

Interdisciplinary health care team

An interdisciplinary health care team consists of two or more individuals with different types of training and skills who work together to provide care based on a person's care plan (see Quality Statement 5).[19] The composition of the team varies depending on the services needed. The team may include various roles, as needed: physicians, nurse practitioners, registered nurses, registered practical nurses, social workers, psychologists, spiritual care providers, pharmacists, personal support workers, dietitians, and volunteers.

Quality Indicators

Process Indicators

Percentage of people who receive palliative care (or their caregivers) who state that they have received care from two or more health care providers, such as a physician, nurse, social worker, psychologist, spiritual care provider, volunteer, and others

- Denominator: total number of people who receive palliative care (or their caregiver)
- Numerator: number of people in the denominator who state that they have received care from two or more health care providers, such as a physician, nurse, social worker, psychologist, spiritual care provider, volunteer, and others
- Data source: local data collection
- Note: the survey respondent will be asked to select all that apply; consider reporting by number and type of health care provider

Percentage of people who receive palliative care (or their caregivers) who state that their health care providers work well together

- Denominator: total number of people who receive palliative care (or their caregivers) from more than one provider
- Numerator: number of people in the denominator who state that their health care providers work well together
- Data source: local data collection
- Similar question available in the CaregiverVoice Survey: "When he/she was at home in the last 3 months of life, did the homecare providers work well together?" (Response options: "Yes, definitely; Yes, to some extent; No, they did not work well together; Don't know")[11,12]

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Team-based care

Team-based care refers to the provision of health services by a group of health care providers who work collaboratively with patients, family, and caregivers to meet their shared goals of care within and across settings of care.

13

Education for Health Care Providers and Volunteers

People receive palliative care from health care providers and volunteers who possess the appropriate knowledge and skills to deliver high-quality palliative care.

Background

People with a progressive, life-limiting illness, families, and caregivers have complex needs; for this reason, those who provide care should have comprehensive palliative care education. Education that focuses on improving communication skills, knowledge, and attitudes about palliative care has a positive effect on a person's experience of palliative care.[24] Competency-based education materials and programs should be tailored to the health care provider's role and responsibilities.

Sources: Ontario Health Technology Advisory Committee, 2014[24] | Registered Nurses' Association of Ontario, 2011[18]

What This Quality Statement Means

For Patients, Families, and Caregivers

You should have access to care providers who are knowledgeable about palliative care and who will work together to meet your needs and goals of care.

For Clinicians

You should receive education to effectively provide quality care for people with a progressive, life-limiting illness in accordance with your role.

For Health Services

Ensure that systems, processes, and resources are in place for health care providers and volunteers to receive the education necessary to provide high-quality palliative care.

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Knowledge and skills

Education should include communication skills, assessment and care planning, advance care planning, and symptom management.[17] It may also include the following[18]:

- Principles and models of palliative care
- Care of the family and caregiver
- Assessment and management of pain and other symptoms (see Quality Statement 6)
- Assessment and management of psychosocial aspects of care, including spiritual and existential issues (see Quality Statement 7)
- Effective and compassionate communication
- Mediation and conflict management
- Advocacy and therapeutic relationship-building
- Ethical issues
- Interdisciplinary practice and competencies (see Quality Statement 12)
- Knowledge of relevant legislation
- Advance care planning, goals of care, and informed consent as described in the Ontario *Health Care Consent Act* (see Quality Statements 3 and 4)
- Self-care, including coping strategies, compassion fatigue, and self-exploration of death and dying

Quality Indicators

Process Indicator

Percentage of health care providers and volunteers who provide palliative care who have evidence of receiving palliative care education appropriate to their role

- Denominator: total number of health care providers and volunteers who provide palliative care
- Numerator: number of providers in the denominator who have evidence of receiving palliative care education appropriate to their role
- Data source: local data collection
- Potential stratification: health care providers, volunteers

Outcome Indicator

Percentage of health care providers and volunteers who provide palliative care who state that they have the knowledge and skills to provide palliative care

- Denominator: total number providing palliative care:
  - Health care providers
  - Volunteers
- Numerator: number of people in the denominator groups who state that they have the knowledge and skills to provide palliative care
- Data source: local data collection
- Note: consider measuring the indicator separately for health care providers and for volunteers

DEFINITIONS USED WITHIN THIS QUALITY STATEMENT

Knowledge and skills (continued)

- Cultural competency and cultural safety, including care for First Nations, Inuit, and Métis peoples
- Palliative care issues in vulnerable populations (people with mental health issues, people who are homeless/vulnerably housed, and people who are incarcerated)
- Social and cultural contexts of death and dying
- Dying trajectories and signs of impending death
- Grief, bereavement, and mourning
- Roles of grief and bereavement educators, clergy, spiritual leaders, and funeral directors

Health care providers and volunteers

These include regulated health care professionals and unregulated care providers.[40, 41] In Ontario, regulated health professions (e.g., physicians, nurse practitioners, registered nurses, occupational therapists) are accountable to their regulatory colleges, which ensure that professionals provide health services in a safe, professional, and ethical manner. Unregulated care providers (e.g., palliative care volunteers, personal support workers) may assist with or perform certain aspects of care traditionally provided by regulated health care professionals, based on their role and employment setting, and are accountable to their employers.

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About Health Quality Ontario

Health Quality Ontario is the provincial advisor on the quality of health care. We are motivated by this single-minded purpose: Better health for all Ontarians.

Who We Are

We are a scientifically rigorous group with diverse areas of expertise. We strive for complete objectivity, and look at things from a vantage point that allows us to see the forest and the trees. We work in partnership with health care providers and organizations across the system, and engage with patients themselves, to help initiate substantial and sustainable change to the province's complex health system.

What We Do

We define the meaning of quality as it pertains to health care, and provide strategic advice so all the parts of the system can improve. We also analyze virtually all aspects of Ontario's health care. This includes looking at the overall health of Ontarians, how well different areas of the system are working together, and most importantly, patient experience. We then produce comprehensive, objective reports based on data, facts and the voices of patients, caregivers and those who work each day in the health system. As well, we make recommendations on how to improve care using the best evidence. Finally, we support large-scale quality improvements—by working with our partners to facilitate ways for health care providers to learn from each other and share innovative approaches.

Why It Matters

We recognize that, as a system there is much to be proud of, but also that it often falls short of being the best it can be. Plus, certain vulnerable segments of the population are not receiving acceptable levels of attention. Our intent at Health Quality Ontario is to continuously improve the quality of health care in this province regardless of who you are or where you live. We are driven by the desire to make the system better, and by the inarguable fact that better has no limit.

About the Ontario Palliative Care Network

The Ontario Palliative Care Network is a partnership funded by the Ministry of Health and Long-Term Care and led by CCO, the Local Health Integration Networks, Health Quality Ontario, and the Quality Hospice Palliative Care Coalition of Ontario. It is putting patients and families at the centre of every decision and strengthening hospice palliative care services across Ontario. This work is person-centred, focused on supporting the provision of quality hospice palliative care for all Ontarians, regardless of their age or disease type. The Ontario Palliative Care Network will help to ensure that hospice palliative care in Ontario is high-quality, sustainable, accessible, continuous, and person-centred.

Notes

Notes

Quality Standards

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Visit our website at **hqontario.ca** and contact us at **qualitystandards@hqontario.ca** if you have any questions or feedback about this guide.

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